

General

Guideline Title

Models of care for cancer survivorship.

Bibliographic Source(s)

Sussman J, Souter LH, Grunfeld E, Howell D, Gage C, Keller-Olaman S, Brouwers M. Models of care for cancer survivorship. Toronto (ON): Cancer Care Ontario; 2012 Oct 26. 58 p. (Evidence-based series; no. 26-1). [71 references]

Guideline Status

This is the current release of the guideline.

The EVIDENCE-BASED SERIES report, initially the full original Guideline, over time will expand to contain new information emerging from their reviewing and updating activities.

Please visit the [Cancer Care Ontario Web site](#) for details on any new evidence that has emerged and implications to the guidelines.

Recommendations

Major Recommendations

Breast Cancer

1. For cancer survivors with breast cancer, if no ongoing treatment issues are observed after the completion of primary therapy (though hormonal therapy may still be ongoing), their discharge from specialist-led care to community-based family physician-led care is a reasonable option.
2. In cancer survivors with breast cancer, if no ongoing treatment issues are observed after the completion of primary therapy (though hormonal therapy may still be ongoing), their discharge from specialist-led care to nurse-led care within an institutional setting is a reasonable option.

Colorectal Cancer

3. In cancer survivors with colorectal cancer who have completed all treatment, discharge from specialist-led care to community-based family physician care is a reasonable option.
4. In patients with colorectal cancer who have completed all treatment, the transition to nurse-led care within an institution may be a reasonable option, based on a similar disease follow-up care trajectory to breast cancer. However, there is insufficient data to inform whether nurse-coordinated care is equivalent to specialist-led.

Prostate Cancer

5. In patients with prostate cancer who have completed primary treatment (radiation or surgery, but with hormonal therapy possibly still ongoing), the transition to nursing-led care within an institution is a reasonable option. Insufficient data exist to inform whether a discharge to primary care is equivalent, but, based on the disease trajectory, the expert opinion is that this is a reasonable option.

Other Cancer Types

6. In patients with melanoma and esophageal cancer, follow-up outside specialist care appears to be acceptable to patients, but without clinical outcomes data, no model of care recommendations can be made.
7. No recommendation can be made about models of care of other disease types based on the currently available published literature.

Nursing Models within Community Setting

8. Nursing models of care within a community care setting appear to be of interest but have not been explicitly evaluated to date.

Shared Care Models

9. No recommendation about the role of shared-care models can be made at this time based on the currently published literature.

Clinical Algorithm(s)

None provided

Scope

Disease/Condition(s)

Cancer

Guideline Category

Management

Clinical Specialty

Family Practice

Internal Medicine

Oncology

Radiation Oncology

Surgery

Intended Users

Advanced Practice Nurses

Hospitals

Nurses

Physician Assistants

Guideline Objective(s)

- To evaluate the models described in the literature for the follow-up care of adults with cancer who have completed treatment and are clinically disease free
- To evaluate if certain models are favoured for survivors of specific cancer types in terms of the following:
 - Clinical outcomes (e.g., surveillance, recurrence)
 - Survivor quality of life outcomes (e.g., quality of life, patient satisfaction)

Target Population

Adults without evidence of disease after primary, curative treatment for any stage of cancer

Interventions and Practices Considered

1. Discharge of cancer survivors from specialist-led to community-based family physician care
2. Transition of cancer survivors to nurse-led care within an institutional setting

Major Outcomes Considered

Clinical Outcomes

- Disease-free survival
- Mortality (cancer-related and all cause)
- Morbidity (late effects)
- Time to recurrence

Quality of Life (QoL) Outcomes

- Quality of life
- Patient satisfaction

Methodology

Methods Used to Collect/Select the Evidence

Hand-searches of Published Literature (Primary Sources)

Hand-searches of Published Literature (Secondary Sources)

Searches of Electronic Databases

Searches of Unpublished Data

Description of Methods Used to Collect/Select the Evidence

Objective 1: Framework Development

The working group reviewed selected articles on the delivery and organization of survivorship care from a targeted scan of documents from leading researchers, specific journals (e.g., Journal of Cancer Survivorship) and from the following Web sites of organizations concerned with survivorship care:

- Canadian Partnership Against Cancer, <http://www.partnershipagaincancer.ca/>
- National Cancer Survivorship Initiative, <http://www.ncsi.org.uk/>
- National Institute of Health, <http://www.nih.gov/>
- National Cancer Institute: Office of Cancer Survivorship, <http://cancercontrol.cancer.gov/ocs/>

The working group came to a consensus on several landmark papers that outlined models of care relevant to current professional knowledge within the Ontario context. These core models were used to develop the framework by which the studies defined in Objective 2 could be described and organized.

Objective 2: Literature Review

Search Strategies

Electronic

OVID was used to systematically search the MEDLINE (R) and EMBASE databases for articles assessing the impact of model(s) of care for post-treatment cancer survivors, published between 2000 and week 13 of 2012. Key terms were purposely broad and included: cancer, survivor, follow-up care and after care, with a subsequent randomized controlled trial (RCT) and systematic review filter. The literature search strategy is reproduced in Appendix 2 in the original guideline document.

Other Sources

Reference lists of primary articles were scanned for potentially useful studies, and selected journals were hand-searched (e.g., Journal of Cancer Survivorship). Websites relevant to care for cancer survivors were searched for evidence-based practice and/or institutional guidelines (e.g., BC Cancer Agency: Cancer Management Guidelines) and recommendations (see Appendix 3 in the original guideline document). The main searches were supplemented by material identified by individual members of the working group. This strategy ensured that pioneering studies published before 2000 were considered.

Study Selection Criteria

Eligible sources of information had to include the following:

1. Peer-reviewed published full reports with information on follow-up care models for adult cancer survivors or examining elements of such models. Follow-up had to be beyond 12 weeks to be considered relevant. The coordinating provider(s) had to be identified and the model(s) clearly defined and, at minimum, include some aspect of medical care and/or surveillance (rather than merely support). If a trial was not explicit in terms of the model(s) being researched, the evidence was still initially considered if the data and results were relevant to the research objectives.
2. Reports published in English.
3. Randomized controlled trials (RCTs), expecting a comparison between a model or elements of a model with another approach. If a trial was not explicit in terms of the model(s) being researched but there were sufficient descriptions to ascertain model or defining feature of survivorship care, the evidence was still considered if the data and results were relevant to the research questions.
4. Systematic reviews identified by the systematic search.
5. Additional sources provided by the working group (such as pioneering studies) if they were relevant to the topic.

The most common reasons for excluding articles were when the articles were not oncology-related, pertained to the active treatment phase, or did not include the target population (e.g., pediatric), or if metastatic disease was diagnosed or the article was not relevant to the present topic (e.g., aspect of support rather than care provision; survivorship focus but not evaluating models of care such as an adjunctive lifestyle program).

Literature Selection

Citations and brief records identified by the search strategy were downloaded electronically into a bibliographic management package (EndNote X5). A research coordinator (SKO) studied the titles from all the searches to identify which abstracts should be obtained. The list of titles was reviewed by a working group member (MB). Following this, two reviewers (JS and SKO) independently reviewed all the eligible abstracts to assess whether the full-text article should be retrieved. Assessments were based on the selection criteria noted. All abstracts categorised as "yes" or "maybe" were then selected for full-text screening.

Studies eligible for full-text screening were saved in portable documents format (PDF) wherever possible; otherwise paper records were kept. Two reviewers (JS and SKO) independently reviewed the full texts for eligibility. The reasons for excluding studies at this full-text stage included the following: a lack of information about who was providing the overall care, treatment included in the follow-up period being studied, a focus on

an adjunctive lifestyle program, and an incomplete final data collection. Two members of the working group reviewed the studies to be included and finalized the list of articles and sources included in the evidentiary base. The studies that met the criteria were retained, and data extraction and analysis followed.

Number of Source Documents

Objective 1: Core Survivorship Models of Care

Five published articles from the literature were selected as a foundation on which to organize models of survivorship care. In addition and although it was in the palliative arena, a report by Cancer Care Ontario (CCO) that described recommendations on the organization and delivery of palliative care in Ontario, was included.

Objective 2: Systematic Literature Search

The systematic literature search yielded a total of 2645 articles and a total of 16 sources were retained for the evidentiary base: twelve randomized controlled trials (RCTs) that addressed different providers or aspects of follow-up care and four systematic reviews that looked at different providers or methods of follow-up care.

Methods Used to Assess the Quality and Strength of the Evidence

Expert Consensus (Committee)

Rating Scheme for the Strength of the Evidence

Not applicable

Methods Used to Analyze the Evidence

Systematic Review with Evidence Tables

Description of the Methods Used to Analyze the Evidence

Critical Appraisal and Data Extraction

Data were extracted by one reviewer, using a predefined form, and audited by a second reviewer independently (see Appendix 4 in the original guideline document). Study quality was independently assessed by two reviewers. For randomized controlled trials (RCTs), no specific instrument was used, but pre-determined criteria included: method of randomization clearly described; whether blinding was employed; power calculations stated; sample size adequate in relation to outcome(s); length of follow-up stated; details of statistical analyses, withdrawal and other losses to follow-up described; and sources of funding declared. The working group members recognised that, due to the nature of the studies being examined, blinding of the model of care was not always possible, and therefore, lack of blinding was not considered a significant weakness in the study design. The methodological quality ratings of the included RCTs are presented in Appendix 5 in the original guideline document. A formal assessment of systematic review quality was not conducted; however, checks were made to ensure the systematic reviews were explicit in how studies were selected (clear inclusion and exclusion criteria) and assessed and clear about attempts to minimize biases and how studies were integrated to form the conclusions.

Synthesizing the Evidence

Due to the anticipated large variation in the outcomes measured and/or how they were reported, pooling the data was not planned but would be considered if the data were to allow.

The reviewers grouped the studies analyzed in Objective 2 as best they could, based on the framework created in Objective 1. Outcomes were reported to have a positive effect if there was a significant difference between the models of care ($p \leq 0.05$).

Methods Used to Formulate the Recommendations

Expert Consensus

Description of Methods Used to Formulate the Recommendations

The methods of approach comprised three parts. To address Objective 1 of the guideline, the working group agreed that an initial framework should be created to inform the development of appropriate models of care for the Ontario setting. A targeted scan was used to identify landmark papers that outlined the core models of survivorship care. These core models were used to develop the framework, which was then used to organize the evidence obtained for Objective 2.

For Objective 2, the core methodology was a systematic review to identify an evidentiary base that addressed appropriate outcomes of the core models of care. The systematic review is a convenient and up-to-date source of the best available evidence on models of care for survivorship. The body of evidence in this review is restricted to randomized controlled trial (RCT) data, comparing at least two models of follow-up care. The appraisal of evidence was conducted by a research methodologist. It was audited, reviewed, and evaluated by the clinical experts in the working group. The appraisal assessed methodology, clinical applications, and feasibility.

The third and final part of the methods involved determining the appropriateness of each model in various cancer types and developing recommendations about potential options for the Ontario setting. The evidentiary foundation from Objective 2 formed the basis of the recommendations developed by the Program in Evidence-based Care (PEBC) Models of Care for Cancer Survivorship Working Group.

Rating Scheme for the Strength of the Recommendations

Not applicable

Cost Analysis

The guideline developers reviewed published cost analyses.

Method of Guideline Validation

External Peer Review

Internal Peer Review

Description of Method of Guideline Validation

Report Approval Panel Review and Approval

Prior to the submission of this Evidence-based Series (EBS) draft report for External Review, the report was reviewed and approved by the Program in Evidence-based Care (PEBC) Report Approval Panel, a panel that includes oncologists and whose members have clinical and methodological expertise. The PEBC Report Approval Panel usually consists of three reviewers, including Dr. Melissa Brouwers (MB); however, since MB is an author of this guideline, the panel consisted of only two reviewers.

External Review by Ontario Clinicians and Other Experts

The PEBC external review process is two-pronged and includes a targeted peer review that is intended to obtain direct feedback on the draft report from a small number of specified content experts and a professional consultation that is intended to facilitate dissemination of the final guidance report to Ontario practitioners.

Following the review and discussion of Section 1: Recommendations and Section 2: Evidentiary Base of this EBS and the review and approval of the report by the PEBC Report Approval Panel, the Models of Care for Cancer Survivorship Guideline Development Group circulated Sections 1 and 2 to external review participants for review and feedback.

Methods

Targeted Peer Review: During the guideline development process, 12 targeted peer reviewers from Ontario considered to be clinical and/or methodological experts on the topic were identified by the working group. Several weeks prior to completion of the draft report, the nominees were contacted by email and asked to serve as reviewers. Eight reviewers agreed and the draft report and a questionnaire were sent via email for their review. The questionnaire consisted of items evaluating the methods, results, and interpretive summary used to inform the draft recommendations and whether the draft recommendations should be approved as a guideline. Written comments were invited. The questionnaire and draft document were sent out on May 25, 2012. Follow-up reminders were sent at two weeks (email) and at four weeks (telephone call). The Models of Care for Cancer Survivorship Working Group reviewed the results of the survey.

Professional Consultation: Feedback was obtained through a brief online survey of health care professionals who are the intended users of the guideline. All nurses, primary care practitioners and oncologists in the PEBC database were contacted by email to inform them of the survey. Six hundred two individuals in Ontario were contacted versus thirty-three outside Ontario. Participants were asked to rate the overall quality of the guideline (see Section 1 in the original guideline document) and whether they would use and/or recommend it. Written comments were invited. Participants were contacted by email and directed to the survey web site where they were provided with access to the survey, the guideline recommendations (see Section 1 in the original guideline document) and the evidentiary base (see Section 2 in the original guideline document). The notification email was sent on May 25, 2012. The consultation period ended on July 9, 2012. The Models of Care for Cancer Survivorship Working Group reviewed the results of the survey.

Evidence Supporting the Recommendations

Type of Evidence Supporting the Recommendations

The recommendations are supported by randomized controlled trials (RCTs), systematic reviews, and a report by Cancer Care Ontario (CCO).

Benefits/Harms of Implementing the Guideline Recommendations

Potential Benefits

- Studies indicate that the transfer of breast cancer survivor care to the patient's usual community-based family physician does not result in an increase in the time to the diagnosis of recurrence. Additionally, when breast cancer survivors are followed by community-based family physicians, there is no difference in recurrence-related serious clinical events or any physical, psychosocial, or quality of life (QoL) components compared to when survivors are followed by a specialist. In terms of survivor QoL, patient satisfaction was greater in the family physician-led community-based care group.
- An equivalence trial found that breast cancer survivors followed by nurse-coordinated care showed no differences in time to detection of recurrence, number of clinical investigations ordered, or psychological morbidity when compared to breast cancer survivors followed by specialist-coordinated care. In addition, women who received telephone nurse-coordinated follow-up were not more anxious as a result of foregoing hospital contact and clinical examinations. A randomized controlled trial (RCT) testing non-inferiority between nurse-coordinated and specialist-coordinated care found that nurse-led telephone follow-up could replace specialist-led institutional visits after breast cancer treatment without adversely affecting health-related QoL, emotional functioning, or anxiety levels.
- The evidence suggests that when colon cancer survivors were followed by a community-based family physician, there were no significant differences for rates of recurrence; time-to-detection of recurrence; death rates; or physical, psychosocial or QoL components compared to when survivors were followed by an institution-based specialist. This finding can reasonably be applied to both colon and rectal cancer populations as the treatment trajectories are very similar.
- The working group was unable to find comparative studies investigating the role of nurse-coordinated follow-up of colorectal cancer survivors. The recommendation that colorectal cancer survivors may be followed by nurses is based on the success of nurse-coordinated follow-up of breast cancer survivors and on the similarity in the follow-up care trajectory between colorectal and breast cancers, where guideline recommended visits and testing can be organized by physicians or nurses within the institutional setting.
- Prostate cancer survivors receiving follow-up care coordinated by a nurse, but still within an institutional setting, showed no differences from those followed by a specialist when the amount of hospital care and the lag time between diagnosed symptoms and intervention was studied. In addition, there were no observed differences between the survivor groups in terms of depression or anxiety. The working group did not

find any studies examining family physician-led follow-up care of prostate cancer survivors; however, given the similar disease trajectory to breast cancer (expert opinion), there is evidence that this model should be further studied for prostate cancer survivors.

- Melanoma survivors receiving family physician-led follow-up care were more satisfied with their care than were survivors followed by specialists. However, this trial did not include any clinical outcomes, and so no recommendation can be made about the effectiveness of the medical care. Similarly, esophageal or gastric cardia cancer survivors followed by nurse-led home visits were equally satisfied with nurse-led compared to specialist-led care after a one-year period. Once again, no recommendation can be made about the effectiveness of medical care from this trial as no clinical outcomes were included in the trial. As survivors appear to be open to alternative care, further studies with survivors of these two cancer types should be undertaken.
- The working group was unable to find sufficient studies that investigated survivorship models of care for cancer beyond those mentioned in the prostate and other cancer type recommendations.
- All studies that evaluated nurse-coordinated care obtained for this systematic review were still within the institutional setting. Given the success of these studies, further research into the efficacy of nurse-coordinated care within a community-based setting are warranted.
- Although shared care has been shown to be beneficial in other disease sites, in the cancer setting, there is not a formalized shared-care model. Due to this lack of formalization, no studies were found that explicitly studied shared care compared to another model in cancer, and thus no recommendation can be made in relation to shared care for survivorship follow-up.

Potential Harms

Not stated

Qualifying Statements

Qualifying Statements

- The working group acknowledges that the randomized controlled trials (RCTs) included in the evidence for the recommendations were completed before the routine use of aromatase inhibitors. For patients in whom a change in hormonal therapy is anticipated, a planned visit with the oncology team may be necessary and should be clearly arranged between the specialist and the nurse or family physician.
- Care has been taken in the preparation of the information contained in this report. Nonetheless, any person seeking to apply or consult the report is expected to use independent medical judgment in the context of individual clinical circumstances or seek out the supervision of a qualified clinician. Cancer Care Ontario makes no representation or guarantees of any kind whatsoever regarding the report content or use or application and disclaims any responsibility for its application or use in any way.

Implementation of the Guideline

Description of Implementation Strategy

An implementation strategy was not provided.

Institute of Medicine (IOM) National Healthcare Quality Report Categories

IOM Care Need

Getting Better

Living with Illness

Staying Healthy

IOM Domain

Effectiveness

Patient-centeredness

Identifying Information and Availability

Bibliographic Source(s)

Sussman J, Souter LH, Grunfeld E, Howell D, Gage C, Keller-Olaman S, Brouwers M. Models of care for cancer survivorship. Toronto (ON): Cancer Care Ontario; 2012 Oct 26. 58 p. (Evidence-based series; no. 26-1). [71 references]

Adaptation

Not applicable: The guideline was not adapted from another source.

Date Released

2012 Oct 26

Guideline Developer(s)

Program in Evidence-based Care - State/Local Government Agency [Non-U.S.]

Guideline Developer Comment

The Program in Evidence-based Care (PEBC) is a Province of Ontario initiative sponsored by Cancer Care Ontario and the Ontario Ministry of Health and Long-Term Care.

Source(s) of Funding

The Program in Evidence-based Care (PEBC) is a provincial initiative of Cancer Care Ontario supported by the Ontario Ministry of Health and Long-Term Care. All work produced by the PEBC is editorially independent from the Ontario Ministry of Health and Long-Term Care.

Guideline Committee

The Models of Care for Cancer Survivorship Working Group

Composition of Group That Authored the Guideline

Working Group: Jonathan Sussman, MD, FRCPC Director, Supportive Cancer Care Research Unit; Lesley Souter, PhD, Research Coordinator, Cancer Care Ontario's Program in Evidence-based Care; Eva Grunfeld, MD, DPhil, FCFP, Clinical Scientist, Ontario Institute for Cancer Research; Doris Howell, RN, PhD, Scientist, Ontario Cancer Institute; Cristina Gage, Clinical Research Manager; Melissa Brouwers, PhD, Provincial Director, Cancer Care Ontario's Program in Evidence-based Care

Report Approval Panel Members: Laurie Elit, MD, MSc, FRCS(C), Lead Scientist, Ontario Cervical Screening Program and Division of Gynecologic Oncology; Eric Winquist, MD, MSc, Medical Director, Clinical Cancer Research Program and Leader, Lawson Translational

Financial Disclosures/Conflicts of Interest

In accordance with the Program in Evidence-based Care (PEBC) Conflict of Interest (COI) Policy, the guideline authors and internal and external reviewers were asked to disclose potential conflicts of interest. All authors and reviewers, except for EG and DH reported that they had no conflicts of interest. EG reported that she has conducted and published several randomized controlled trials (RCTs) on follow-up care of breast cancer survivors, as well as editorials/commentaries on the subject. DH reported that she has received a grant to research models of survivorship care and has published a review on the subject.

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Guideline Availability

Electronic copies: Available in Portable Document Format (PDF) from the [Cancer Care Ontario Web site](#) .

Availability of Companion Documents

The following is available:

- Program in evidence-based care handbook. Toronto (ON): Cancer Care Ontario (CCO); 2011. 15 p. Available in Portable Document Format (PDF) from the [Cancer Care Ontario Web site](#) .

Patient Resources

None available

NGC Status

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